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# **‘AM I BEING HEARD?’ THE ‘VOICE OF’ STUDENTS WITH DISABILITY IN HIGHER EDUCATION: A LITERATURE REVIEW**

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## Abstract

Research in higher education suggests the need for higher education to show greater understanding and awareness of the lived experiences of disabled students. These sources argue that knowledge and understanding of barriers that this group of students face may be conducive to facilitate inclusive and effective teaching strategies. Although the needs and rights of disabled students as learners in higher education are officially recognized, there remains a gap between changes guaranteed by legislation and actual support and accommodation available in higher education institutions. Researchers have attempted to bridge this gap by listening to the ‘voice of’ disabled students and actively engaging them in higher education research on issues concerning them. The aim of this review article is to contribute new knowledge by mapping students with disability experiences of barriers to higher education as they emerge in research conducted by scholars who specifically elicit their voice. The review documents the experiences of students in 41 studies between 1996 and 2013. Findings suggest that listening to the voices of disabled students may be an appropriate method to engage students and encourage inclusive participation in actions to dismantle barriers and resolve challenges to the benefit of both students with disability and higher education institutions.

*Keywords: barriers; disability; disabled students; higher education; students with disability; voice*

## Introduction

For students with disability participation in higher education is a matter of equal opportunities and empowerment. A demand for inclusion in higher education on par with other students has served as a uniting force. Pressure from disabled people's organizations, students, the disabled themselves and civil society in general have made discussions about diversity and social inclusion of disabled students in higher education a topical subject. At the institutional level their demands have resulted in anti-discrimination legislation. The Universal Declaration of Human Rights (UDHR) 1948 recognized the right to education, the Salamanca Statement and Framework of Action (1994) committed signatory countries to inclusive education for people with disability. In addition, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) guaranteed the fundamental rights of people with disability to higher education on an equal basis with others in the communities in which they live. Sweden is a signatory to all three of these important agreements.

Importantly, whilst signatories to the UNCRPD officially recognized the needs and rights of disabled students as learners in higher education, synchronizing national legislation, policy, and financial resources to incorporate fully students with disability into higher education has moved more slowly. The Nordic countries, Australia, USA, UK, India, and Israel are examples of countries that have enacted national legislation concerning integration of disabled students into higher education. However, the impact of legislation has been the subject of several analyses (Beauchamp-Pryor, 2012; Leyser et al., 2000). Critics while praising the initiative have argued that although legislation enhances the opportunity for students with disability to enter higher education, enactment of legislation seldom provides economical or other resources. For example, commenting on the Australian Disability Discrimination Act of 1992, MacLean and Gannon (1997) argue that although the Act "makes it unlawful to exclude people with a disability, it does nothing to support people with a disability to achieve positive support from the university community, it also fails to specify what might be 'reasonable support'" (1997: 217). Alternatively, higher education policy-makers responded to political demands for increased presence of under-represented groups improving conditions for students with disability by framing and by adopting policies within the discourse of widening participation. Widening participation called for the inclusion of a broader spectrum of non-traditional students including those with disability, thereby charging European higher education institutions with improving access to higher education as well as facilitating of completion of studies for non-traditional groups, a requirement that demanded institutions reevaluate their understandings of students' rights. The initial response to anti-discrimination legislation was the implementation institutional level anti-discrimination policies and the establishment of disability support offices to provide support services aimed specifically at reducing barriers to education for students with disabilities (Tinklin and Hall, 1999; Fuller et al., 2004; Brandt, 2011; Beauchamp-Pryor, 2012).

Despite these initiatives, students with disability as proportion of student populations in colleges and universities remain small. In the United Kingdom where research has focused students with disability since the 1970s, students with known disabilities composed 6.5 percent of student populations in 2006-07 a mere four per cent increase from 1994-95 (Ebersold, 2008). In Sweden only 2.6 per cent of students in higher education declared a disability in 2012 (Högskoleverkets års rapport 2012, [www.studeramedfunktionshinder.nu](http://www.studeramedfunktionshinder.nu)). The most common reasons cited by countries for under-representation are insufficiently adapted infrastructure, lack of appropriate teaching and learning materials and funding problems. The same issues prevail in compulsory education with several countries, including Estonia and Hungary, mentioning the negative im-

pact of segregated schools in primary and secondary education (EURYDICE, 2010). A few countries mentioned psychological barriers created by perceived negative attitudes towards disability. The exceptions were Liechtenstein and the United Kingdom (Scotland) that mentioned the lack of a 'disability acceptance culture' within higher education institutions and the negative impact of stereotyping (Crosier and Parveva, 2013). The accounts from these countries' fit well with research findings that improving the socio-psychological environment in higher education is at least as important as adapting physical infrastructure (Shevlin, Kenny and McNeela, 2004; Williams, 2011).

The above presented accounts do not include discussions of difficulties students with disability encounter when transitioning to higher education or barriers to completing educational courses if accepted. Research shows that aside from physical barriers such as access to buildings, classrooms and other spaces, access to learning materials disabled students frequently suffer from restricted social networks, and experience higher risk of failure and drop-out than do non-disabled students (Madriaga, 2007; Lang, 2013). Furthermore, even when higher education institutions provide dedicated disability support services, resources for these services remain smaller than existing need (Riddell et al., 2005; Fuller et al., 2009).

Thus, even as higher education institutions (hereafter HEIs) become more inclusive of disabled students, students with disability continue to perceive barriers to education. These perceptions may be the result of both actual differences in physical environments and or the treatment of students in the classroom and the inability of educators to understand and be sensitive to and inclusive of them in teaching styles and content. Alternatively, they may result from the inability of disabled students to make their voices heard when policies are conceptualized and implemented. As a result, arguments from a variety of sources call for active involvement and participation of students not only in the discourse of higher education but also in policy-making (Carney, 2013; Boxall et al., 2004). Barnes (2007) observes that to understand the relationship between political activism, i.e. the struggle for acceptance in the academy for students with disabilities, there is a need to come to terms with universities historical conservatism. It is only recently he argues that higher education institutions have become the site of progressive change resulting from activism both inside and outside of the university. Thus, for reasons of legitimacy, higher education research must be inclusive of the voices of students with disability (Barnes, 2007; Barnes and Mercer, 2004).

Whilst the needs and rights of disabled students as learners in higher education are officially recognized, research shows that there remains a wide gap between changes guaranteed by legislation and actual support and accommodation available within higher education institutions. Furthermore, higher education institutions have been slow in including student's voices in policy-making, a process that potentially could improve outcomes for both parties – students and universities (see e.g. MacDonald and Stratta, 2001 for the early UK context; Osborne, 2003 for development in Europe and OECD countries; and Martinsson, 2009 for a view of Sweden). This however is not a chore for universities alone. Scholars and practitioners must also participate in these efforts, by conducting studies of students' experiences in higher education they contribute new knowledge and function as facilitators providing incentives for both students and universities to engage in the dialogue. The purpose of this literature review is to map and summarize the manner in which researchers have embraced this task. The aim is to explore how research documenting the experiences of disabled students in higher education contributes to ongoing dialogue between students and higher education policy-makers. This is an appropriate task as the field of disability studies starts from the position that to be relevant research on marginalized

groups must be inclusive of them. Consequently, a careful listening to students is a key requirement in order to understand what impact reforms have on the ability of students with disability to meet challenges attending higher education entail. As a new focus of study, there is much to be done; Fullan argues that, “/.../ we hardly know anything about what students think about educational change because no one ever asks them” (1991: 182). Levin contributes to this discourse with his comment that, “the history of education reform is a history of doing things to other people, supposedly for their own good. Each level in the hierarchy of education believes it knows best what those at lower levels need to do, and has little shyness about telling them or, just as often, forcing them” (Levin 2000: 155).

The lack of inclusion of marginalized groups in educational issues is particularly disadvantageous for students with disability. In an often-cited text, Hurst urges researchers to “identify both the concerns relevant to all disabled students and those specific to a particular group” (1996: 133). Further, in the same text, he argues for researchers to address this gap in knowledge using a variety of methods and methodologies. Reflecting on these challenges, Carey (2013) argues that listening to the voices of disabled students is appropriate in higher education because doing so provides a better understanding of barriers to higher education and opens up a dialogue to address key challenges that both institutions and students might face. In response to the challenge set by Hurst and Levin, the aim of this literature review is to contribute towards filling the knowledge gap by exploring students with disability experiences of barriers to higher education as they emerge in research conducted by researchers who specifically elicit their voice. This literature review documents the experiences of students in 41 studies carry out between 1996 and 2013. Organization of the article is as follows. The next section presents and discusses the search method including a descriptive presentation of the extracted studies, followed by a thematic presentation of the findings. The article ends with some conclusions and limitations.

## Search method

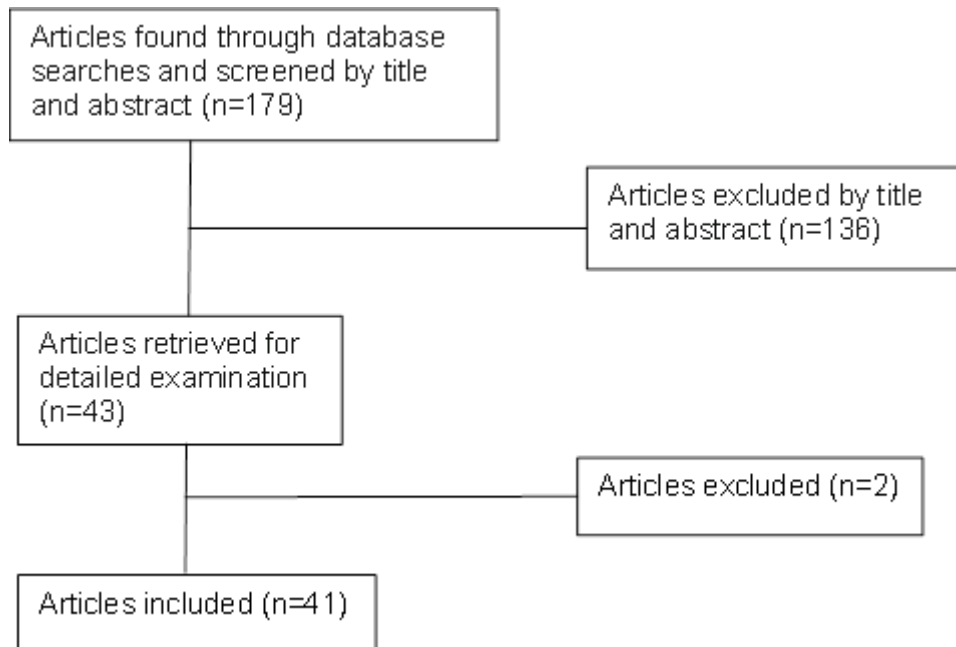
In general, this literature review follows principles and processes of systematic reviews, defined as an undertaking “that uses a specific methodology to produce a synthesis of available evidence in answer to a focused research question” (Bearman et al., 2012: 627). In particular, it adopts a systematic procession from one stage to the other with as much transparency and explicitness as possible about what research is to be critically evaluated and appraised.

Taking on board criticisms that systematic reviews may not be conducive for reviews based primarily on qualitative research with a myriad of methodological perspectives, the review adopts a scoping study approach. The aim of scoping or mapping is to, “rapidly map the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before” (Mays, Roberts, and Popay, 2001: 194, cited in Arksey and O’Malley, 2005: 21). While remaining rigorous, scoping offers flexibility in deciding what information to collect from the primary studies while keeping in mind possibility for comparisons. Arksey and O’Malley recommend a ‘descriptive-analytical’ method within the narrative tradition, which involves applying a common analytical framework to all the primary research reports and collecting standard information on each study (Arksey and O’Malley, 2005: 26).

## **The Search process**

According to Tight, we should keep two key factors in mind when undertaking this type of research, the project should be of interest for the researcher, and it should be feasible (Tight, 2012). For that reason and in line with the aim as presented above, the search process uses a scoping approach to delimit peer-reviewed studies in English language journals that elicit higher education experiences of disabled students as articulated in their own voice between 1996 and 2013 (inclusively). Starting at the broadest possible range, an initial search using the following keywords: higher education, university and college, disability, student, students with disability, accessibility and support in higher education and “voice,” was undertaken in the ISI Web of Knowledge, Scopus, ERIC, Education Research Complete, Academic Search Elite and Teacher Reference Center. Studies were included in the search if they were published in a peer-reviewed English language journal, if the study focused the experiences of students in higher education between 1996 and 2013 (inclusively). A search using the above criteria identified 179 articles (see Figure 1). After viewing title and abstract, 136 of the identified articles were excluded as they did not fit the selection criteria or were duplicates. Full texts of the remaining 43 studies were retrieved for detailed and independent examination. In this process, two articles were excluded because they did not meet all of the selection criteria, leaving 41 studies to be included in the review. In accordance with the scoping approach suggested by Arksey and O’Malley (2005), the following data were initially extracted from each article in order to facilitate comparisons: author(s); year of publication; country within which the study took place; journal name; research aim; study design and data sources.

**Figure 1**  
Presentation of the search procedure



## Descriptive presentation of included articles

Disability studies were still in its infancy when Hurst called for researchers to be inclusive of the voices of disabled students as an area of study within sociology. Researchers were beginning to identify and delimit what disability study was and should be as an academic subject, the following presentation reflects this development. In 1996 when this review begins, researchers were slowly becoming inclusive of student voices. Interest in exploring the voice of students with disability developed and became increasingly the focus of research with the establishment of a journalistic voice with the goal of disseminating new knowledge and research from the developing field of disability studies. The journal, *Disability and Society*, founded in 1994 to replace *Disability, Handicap and Society* represented a new direction embracing both the social model of disability and a focus on participatory research. It is therefore not surprising that 13 of the 41 articles included in this review were published in that journal (see Table 1). The second largest number of articles, six were published in *Studies in Higher Education*. Although publishing notably fewer articles, other journals play important roles by offering a broad array of researchers' opportunity to explore student experiences in various fields of education and educational research and thus contribute to the ongoing debate.

Table 1 also reveals the importance of geographical location. Twenty-five of the forty-one articles focus research in the United Kingdom – twenty studies in England, two studies from Ireland, one from Northern Ireland and two from Scotland. The other studies focus the European



context with Scandinavian countries represented in five articles and other European countries in eight articles. The remaining eight studies focus studies in other parts of the world, two in the USA, two in Canada, two in Australia, one in New Zealand, and one from Botswana. Studies from the USA are under-represented in the review and Asia and Latin America are not represented at all.

Compared to other countries, the UK dominates in the number of published studies, for example, the first non-UK study in the review was published in 2008, and studies from Scandinavian countries appeared first in 2012. The UK dominance may be explained by the emergence of a disability movement, which took place earlier in the UK than in other European countries. Cooperation between individuals, disabled peoples organizations, and academics within the movement to promote social change is reflected in an increasing number of studies that take their point of departure in student's experiences of agitation for and the implementation of support services for students with disability.

<i>Table 1</i>	
Number of articles per Year, Academic Journal in which the research appeared and Country of study for each	
<b>a) Number of articles per Year</b>	
<b>Year</b>	<b>No. of articles</b>
1996	1
1999	2
2001	1
2004	3
2006	1
2007	3
2008	2
2010	6
2011	7
2012	8
2013	7
<b>b) Number of articles per Academic Journal</b>	
<b>Academic Journal</b>	<b>No. of articles</b>
British Journal of Sociology of Education	1
Disability & Society	13
Dyslexia	1
Higher Education	2
International Journal of Disability Development & Education	2
International Journal of Inclusive Education	4
International Journal of Psychology	1
International Journal of Rehabilitation Research	1
Journal of Computer Assisted Learning	1
Journal of Diversity in Higher Education	1

<b>Table 1</b> Number of articles per Year, Academic Journal in which the research appeared and Country of study for each		
Journal of Learning Disabilities		1
Journal of Policy and Practice in Intellectual Disability		1
Journal of Research in Special Educational Needs		1
Medical Education		1
Scandinavian Journal of Disability Research		2
Studies in Higher Education		6
Support for Learning		1
Widening Participation and Lifelong Learning		1
<b>c) Number of articles per Country</b>		
<b>Country</b>		<b>No. of articles</b>
Australia		2
Botswana		1
Canada		2
Cyprus		2
New Zealand		1
Norway		3
Sweden		2
Turkey		1
UK		25
England	20	
Ireland	2	
Northern Ireland	1	
Scotland	2	
USA		2

## Findings

Finding from the literature study are organized and presented thematically. The first theme discusses the development of a theoretical frame for disability studies, followed by findings and discussions of themes related to methods and methodologies, disability terminology, and barriers to higher education. The theme barriers to higher education is divided into four sub-themes each discussing a central emerging factor that contributes to or limits disabled students participation in higher education. The literature review engages in dialogue with research from the fields of disability studies and higher education to contextualize and inform findings within each theme.

## **Same river different streams – theoretical approaches to disability studies**

Central to advancement of disability studies has been the development of theoretical approaches focusing inclusion, emancipation, social justice, and empowerment. As an academic discipline, the aim of disability studies is to examine and theorize the social, political, cultural, and economic factors that define disability. As noted above, these ways of theorizing developed in close alignment with disability movements in Europe and the United States. To the people involved, it was important that the disability movement reflected the views and aspirations of disabled people. The struggle was premised on the idea disabled people were capable of understanding and articulating their experiences of disability and the rallying call, “nothing about us without us” was a starting point for participatory research frame that included many of the front line figures in the movement and the academy who were themselves disabled (Abberley, 1987; Barton and Oliver, 1992; Oliver, 1989; 1990; Thomas, 1999).

All of the studies included in this review are implicitly or explicitly inclusive of a disability studies perspective and embrace the social model of disability. All of the studies pay homage to the disability movement and struggles for inclusion and recognize contributions of leading lights in the movement such as Oliver, Hurst, Barnes, Shakespeare, and Thomas. In the various studies, Oliver’s research is cited 31 times, Hurst 18, Barnes 12, Shakespeare, and Thomas are cited 6 times each. Other researchers that made significant contributions to development within disability theory and cited in the studies are Finkelstein, Bury, Watson, Barton, and Williams, all pioneers of disability studies and the social model. Exceptions to the discussion above are the American studies.

While the USA studies explicitly evoke the ‘voice of’ students and by investigating barriers for specific groups of disabled students in higher education and implicitly makes use of the social model of disability, neither of the two studies cites or makes specific reference to the social model or its European advocates. Furthermore, the fact that only two articles from the United States emerged in the search was a cause for concern. Was the search process incorrectly designed resulting in the exclusion of research from the USA or could other reasons explain the lack of research? The search for possible explanations begins with an examination of tensions and divisions surrounding the social model of disability.

At its inception, the social model of disability developed in opposition to the medical model of disability. A distinguishing characteristic of the medical model is the assumption that disability is located within an individual who has impairment. Thus, disability is conceptualized as an individual limitation that can be counteracted by individual rehabilitation and as such, societal change plays an insignificant role. The medical model is associated with negative stereotypes that view people with disability as having problems that make them different from ‘normal’ people (see e.g. Jaeger and Bowman, 2005; and Lindqvist, 2007 for a Swedish perspective).

The social model challenges medical model assumptions, arguing that disability is constructed through social, structural, and environmental barriers rather than an individual’s impairment. Proponents of the social model argue that, there is no causal link between impairment – the body’s biology and disability. Disabled people may experience life difficulties because of the state of their body, but that is something entirely different compared with the difficulties caused by a society that is constructed without regard to the variety of peoples living in it. Thus, disabili-

ity is a particular form of discrimination and this discrimination has social causes (Oliver, 1996; Lindqvist, 2007).

The social model of disability dominates disability study discourse but it is not without its critics. New directions in disability research situated within in the framework of post-modern theorizing have emerged (Corker, 1999; Shakespeare and Watson, 2001; Corker and Shakespeare, 2002). Post-modern thinking emphasizes the cultural construction of embodied experience and identity, and the significance of 'difference' in disabled people's lives. Post-modernist accept the social model's core understanding that social processes and cultural meanings structure the lived experiences of disabled people but argue that the focus on the impairment/disability dichotomy and issues of identity has made it less useful for analyses of post-modern societies. Both concepts, impairment and disability, they argue, are created discursively and as such, it is contextually dependent on barriers to access and need to be interrogated as cultural constructions. The challenge they argue is to move beyond the dualism position to make impairment and disability equally important in analyses (Shakespeare and Watson, 2001).

Feminist researchers, among them Carol Thomas argue for another way of theorizing disability. They have sought a middle ground between researchers following the social model and those working from a post-modern perspective. Thomas claims that Shakespeare and Watson's main criticism of the social model is based on a misunderstanding of the model's conceptual separation of impairment from disability and its assertion that people with impairment are disabled by society, not by their impairments (Thomas, 2003; 2004). Thomas argues, "Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas, 1999: 60). What critics have missed she claims is the social relational view of defining disability. Disability only comes into play when the restrictions of activity experienced by people with impairment are socially imposed. In this respect she argues, the researcher should acknowledge that impairments and chronic illness directly causes some restrictions of activity, but that non-socially imposed restrictions of activity do not necessarily constitute 'disability' (Thomas, 1999).

In sum, the medical model approach reduces functional limitations in mind or body to an individual concern and stresses medical treatments and rehabilitation. The social model defines disability as a form of social oppression where people with impairment become disabled or excluded from everyday life by social and environmental barriers, attitudes, and practices (Oliver, 1996; Barnes 2007). Both models serve to illustrate how society's view of people with disabilities has evolved from merely meeting their health needs to seeing the obstacles in society that create them. Even as we take on board critique of the social model, it continues to dominate the disability study discourse in Europe.

In contrast to the British disability movement, which engaged scholars within higher education, in the USA, the disability movement started already in the 1960s as a part of the civil rights movement. While taking its point of departure in opposition to the medical model, the American variation of the social model was distinctively different from the UK model. Shakespeare argued that while Americans were inclusive of a social approach to disability, ".../as is illustrated by the US term 'people with disabilities', these perspectives have not gone as far in redefining 'disability' as social oppression as the British social model. Instead, the North American approach has mainly developed the notion of people with disabilities as a minority group, within the tradition of US political thought" (Shakespeare and Watson, 2001:4).

Tracing its origins back to the Civil Rights movement in the 1960s, the disability movement in the USA, focuses two distinct models. The Independent Living Model (ILM) is a consumer driven movement demanding autonomy, self-help, and removal of societal barriers and disincentive for impaired people. The demands of the ILM were the first documented shift away from the then prevalent medical model. As De Jong (1979), one of the founders and activists within the movement argued, it is social and political structures that produce barriers that create dependency in people with impairments resulting in their disability.

The second direction in the USA is the Minority Group Model (MGM), which adopted the same point of departure as the ILM but with the further distinction that structures generate barriers that discriminate impaired people resulting in disability. The Minority Group Model (MGM) politicized the shift focused in the ILM by positioning it in a civil rights perspective. The goal of the movement was to motivate and agitate for political and policy change and the development of research strategies to combat discrimination (Hahn, 1985).

Both American models argue that disability is a socio-cultural rather than a biological construct, “the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities rather than from the inability of the disabled individual to adapt to the demands of society” (Hahn, 1986: 132). As such, disability is viewed as a societal rather than an individualistic issue separate from existing power relations and social structures. Furthermore, there is a need to accept that people with disabilities can best identify their own needs and can lead productive lives in the community through self-help, empowerment, and the removal of barriers.

What the American models share in common with the UK/Europe social model is a rejection of the medical model’s focus on the individual and the centrality of social processes and cultural meanings for understanding disabled peoples’ oppression and opportunities. A major difference is that while the UK disability movement engages scholars within higher education making the conditions for students a topical subject, the American disability movement focuses on assisting individuals with disabilities to become active functional members of society outside the academy. The differences in focus of the American and UK social models provide some insight to understanding why there appears to be a delayed reaction to the plight of young disabled people in higher education, but it does not explain why the search revealed so few American studies. The conclusion drawn is that the narrowness of the search may have inadvertently excluded American studies, thus in effect this is a review of the European context with studies from the rest of the world thrown in as interesting but underrepresented cases.

## **In whose interest? Participatory methods and methodology**

Theoretical approaches focusing the centrality of the social model of disability limited the choice of methods and methodology available to researchers in their studies. The goal to hear and represent disabled peoples introduces possibilities to embrace more participatory methods. Participatory research refers to research that actively engages individual participants in the research process (Chappell, 2000), the aim of which is to give members of marginalized groups a voice, or to enable them to make their voices heard. What counts is that they bring their experiences, their everyday knowledge, and their ability into the research process and thereby gain new perspectives and insights (Russo, 2012).

A close related but different approach is emancipatory research that assumes that the participant not only participates in the research but is also in some respects in control of the research pro-

cess (Oliver, 1992; 1997; Barnes, 2004). Both strands of participatory research emerged with strong connections between the British social model of disability and the UK disabled people's movement (Barnes 2004; Boxall et al., 2004).

As studies in this review attest to, participatory methods opens up for research to initiate dialogue between researchers and participants, but it is this intimate relationship that raises critic. First, critics challenge the right to represent and speak for others. Problematizing the 'voice of' concept they argue that there are no justifications for speaking for others (see e.g. Hinterberger, 2007; MacLure, 2009; Mazzei, 2007). While others support the idea, for example Alcoff (1991) argues that speaking for others requires careful attention and bears with it demands for accountability and responsibility for what is said, how it is said and for which audience. Furthermore the impetus for the 'discursively privileged' to speak must be carefully weighed and analyzed.

The second major critique follows from Alcoff apprehensions concerning discursive privilege, which raises the issue of uneven power relations between the researcher and the participant. The 'voice of' approach requires the researcher to listen to the voice of the researched. However, the ways in which people get involved in a participatory research project, or to speak, write or perform as part of a project and its dissemination activities, emerge within a complex web of power relations. The problem as Cooke and Khotari, (2001) argue is that when researchers function as intermediaries between participants and dissemination activities, ambiguity may arise concerning how the results of that 'listening' are reported revealing unspoken inequitable power relationships between researchers and participants. Thus, a 'voice of' approach has the potential to reinforce and reproduce existing socio-political structures if they only promote the voices and values of those who are most articulate, alternatively easily available individuals or if only those with prominent positions are allowed to speak for others. Equally damaging a failure to recognize and address uneven power relations between participant and researcher may result in further marginalization of an already marginalized group. Examples relevant for this review are the challenges and conflicts that arise for academics (disabled or not) who also have other agendas to pursue. Aside from an overt desire to serve the interests of disabled people the demand to produce academic publications, preferably single-authored and to achieve all this as quickly as possible is also a part of their agenda (Barnes, 1996; Shakespeare, 1996).

The findings show that consistent with a 'voice of' participatory approach, the majority of the studies in this review employed a qualitative method (Chappell, 2000; Goodley et al., 2004). In addition, a few researchers framed their research within a particular theoretical perspective. Examples are grounded theory as advocated by Strauss and Corbin (1990), Lincoln and Guba (1985) or Charmaz (2005). Others were more exploratory; Hopkins (2011) employed a voice-relational analytical method developed by Brown and Gilligan (1992) to explore personal narratives of students' experiences of discrimination in higher education. Gibson and Kendall (2010) employed Chappell (2000) and Goodley et al. (2004) to study the transition of students with dyslexia from high school to higher education in order to understand factors that affect self-esteem and academic achievement. Moore (2010) and (Bessant, 2012) explored students' experiences of trying to access alternative assessment methods using an ethnographic case study approach in combination with Norbert Elias' personal pronoun model to analysis perceptions, attitudes and interactions between actors engaged in determining and granting access to alternative forms of assessment. Finally, Hutcheon and Wolbring (2012) applied a thematic network analysis developed by (Attride-Stirling, 2001) to derive primary themes in their study of how students make sense of their experiences of disability.

Researchers while trying to understand the complexities of students' experiences were also aware of their roles as advocates for reforms to change and improve the situation for students in higher education, i.e. the researcher and the object of research - students were interlinked within the context of the situation that shaped the inquiry (Guba and Lincoln, 1994). This ambition is reflected in the number of students included in the various projects. Sample size ranged from a case study of one student to a large sample of 1336 students. A few studies focused one gender while the majority included both female and male students. Only one study explicitly included ethnicity as a variable and none presented cross-national comparisons. The majority of informants were under-graduate although a few included graduate students, one of which focused exclusively on the experiences of one graduate student (Jacklin, 2011).

<i>Table 3</i> Methods and methodological approaches	
<b>Methods</b>	<b>Number of articles</b>
Quantitative surveys	9
Qualitative	31
In-depth interviews	
Focus groups	
Case study	
Time-geographic diary	
Storytelling/narratives/life histories	
Concept mapping	
Audio recording	
Observation: Video Shadowing	
Mixed methods	2
Survey and interviews	

Table 3 presents the method and methodological approaches adopted by researchers in the reviewed studies. As shown, 31 of the 41 studies used qualitative methods, nine quantitative and two articles a mixed-method combining qualitative and quantitative method. The qualitative studies represent a wide variety of data collection methods, often used in combination with each other as a form of triangulation. Further, in a number of the studies researchers gathered student voices repeatedly interviewing them several times over the course of their projects. Tinklin and Hall (1999) provides an interesting example, employing a combination of shadowing, open-ended interviews with follow-up interviews conducted the following year to investigate the experiences of support provision for 12 students with physical and mental disability and learning disability.

Fuller et al. (2004) provides an example of how quantitative methods were used to explore the 'voice of' approach. In their study, the authors explored the experiences of barriers to learning in higher education for 173 students recruited from the National Bureau for Students with Disability (SKILL) using a questionnaire. The study demonstrates not only the use of the method but also underlines the relationship between the academy and disability organizations in the UK. Other studies employing quantitative methods in a novel manner were Mortimore and Crozier

(2006) study of study skills among male students with diagnosed dyslexia and non-diagnosed students and Madriaga et al. (2010) large scale of learning disability to better understand ableism.

Although under-represented in this review, studies using mixed-method approaches appeared in the latter period of the study. Beauchamp-Pryor (2012) adopts a mixed-method approach to explore representation and participation of disabled students in the development of higher education policy and provision. She approaches the problem using a questionnaire in combination with unstructured interviews including 23 students with a variety of disabilities, age, gender, socio-economic backgrounds representing different courses and levels of study. Another example is Simmeborn Fleischer et al. (2013) exploratory study of ADHD.

Relevant to this review and central to disability studies is the premise that disabled people are not a socially homogeneous group. Reflecting on critics fear, that relying principally on ‘voice of’ participatory approaches might further exacerbate the situation for an already marginalized group the findings show that fears were both realized and allayed. Looking first at how participatory approaches may be a cause for concern. Few studies paid serious attention to diversity, thus, while gender was noted, consequences of gender and disability or gender /ethnicity and disability for biological bodies were seldom analyzed. Discussions of widening participation raised issues of inclusion for non-traditional students including students with disability, however, analyses did not include discussions of how various societal hindrances such as lack of economic and social capital collude and over-lap to exacerbate their marginalization. In this respect, the findings show that researchers’ analyzed disabled students as if they composed a homogeneous group.

On the other hand, by lifting up the plight of all disabled students the finding show that researchers could dispel fears of using participatory approaches. Using a ‘voice of’ approach researchers were able to find common grounds of interest to broad categories of disabled people among these are studies investigating the importance of legal institutions as the foundation for rights based demands.

## **Am I that name? Naming and labeling in disability studies**

The meaning given to the term ‘disability’ and the multitude of ways it is experienced depends on who is defining it, for whom it is defined and for what purpose. In an attempt to capture these varieties, the UNCRPD defines disability as “an evolving concept” that “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (UN Convention, 2006). The UNCRPD definition recognizes the relationship between body, performance, and environment in shaping the meaning of disability. It also recognizes how these relationships contribute to discrimination against people with disabilities. In higher education, the category disability is inclusive of a broad array of issues, contexts and disability types that extend across individuals, groups and within different educational contexts. There seems to be broad consensus in recognizing that belonging to the disability category results in significant barriers to equal education and thereby contribute to lower educational attainment, higher unemployment and greater poverty (Shaw, 1998). In higher education, the scope for individual interpretations of disability as a discursively constructed category generates a need to distinguish between those fitting within the category and those outside of it.



The findings reveal that in the struggle for limited resources provided by university student support services the emergence of various labels to categorize students. The recognition that students with disability are a heterogeneous group often experiencing multiple forms of impairment in the same body complicated the naming and labeling game even further.

Until now, no label or term has acquired hegemony within the field of disability studies. However, several have been contenders. The first label that sought to encapsulate the meaning of disability for students in higher education emerged in dialogue with the social model of disability that grew from the collective efforts of disabled people and their organizations (Finkelstein, 1980; Abberley, 1987; Oliver, 1990). Rather than emphasis exclusion this group defined disability as: “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.” UPIAS cited in Tinklin and Hall, 1999: 185). Thus, as articulated by Oliver, [...] it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (Oliver, 1996: 22). From this definition emerged ‘disabled student’ a term used to indicate how students are disabled by their environment.

The findings show that this terminology was the point of departure for many of the included studies (see e.g. Baron et al., 1996; Tinklin and Hall, 1999; Beauchamp-Pryor, 2012). Others for example Claiborne (2009) prefer students with impairments. While yet other group use both labels interchangeably (see e.g. Redpath et al., 2013). As researchers became interested in barriers to higher education that extended beyond physical barriers, terminology expanded to include various forms of learning disability (LD) (Madriaga et al., 2010) or specific learning disability (SpLD) (Mortimore and Crozier, 2006). The term ‘students with disability’ is first noted in Borland and James (1999) study of the educational experiences of students with disabilities in relation to services stipulated in British university Disability Statements. Although, used to explore the experiences of students with physical disabilities, the findings show that other researchers use the term to signify the inclusiveness of all forms of disability and awareness that disability is not a person’s most important attribute (Goode, 2007 and Cook et al., 2012).

The naming game becomes even more complex when we accept that people with disability are a heterogeneous group often experiencing multiple forms of impairment in the same body. To address this diversity an emerging area of research - ableism has adopted the term ‘ability-diverse populations.’ Recognizing the contentiousness of language and how it is used two proponents of the ableism concept, Hutcheon and Wolbring argue for a return to the ‘disabled student’ label as it “reflect the belief that those who possess bodily or functioning differences are disabled by social, cultural, and economic structures and systems of meaning” (2012:39). With a return to the ‘disabled student’ label the disability discourse could be inclusive of diversity of ability or ableism, i.e. the recognition and understanding of the sociocultural production of ability (Madriaga, 2007; Vickerman and Blundell, 2010; Hutcheon and Wolbring, 2012).

In sum, our findings suggest, that the labels researchers use to address students in their studies reflect perceptions of the inclusiveness of specific groups within the disability discourse. They also mirror the struggle for resources as the power of labels to draw attention to the plight of excluded groups and with pervasive arguments as agitation for inclusive practices become more visible in higher education.

While labeling draws attention to students as disabled their impairment/disability forms the bases for securing resources in higher education. To ensure efficient use of limited resources, higher education institutions document students' type of disability reporting the number and type of provisions delivered. The list presented in Table 2 although differing slightly from formal statistical tables used to list disability for cross-country comparisons attempts to capture the full range of disability/impairment that emerged in the findings.

<i>Table 2</i> List of disabilities mentioned in the review studies	
1	Chronic disease (e.g. asthma diabetes epilepsy HIV ME
2	Combination of physical impairment and other difficulties
3	Deaf/sign language speaking students (with interpreting)
4	Hard of hearing students(without interpreting)
5	Mental health issues (e.g. depression, bipolar disorder)
6	Multiple physical impairment
7	Neurological developmental disorders (e.g. ADHD ADD Tourette syndrome)
8	Students with mobility impairment
9	Students with specific learning difficulties (e.g. dyslexia dyscalculia)
10	Students with visual impairment
11	Students with other unspecified conditions

Although not the focus of this review, it is interesting to note that as the number of students with recognized disability increase the category 'students with other unspecified conditions' has also increased (see e.g. development of categories for Sweden at Studera med funktionshinder.nu). In this review, researchers were inclusive of students with a broad range of both 'visible' and 'invisible' disabilities. However, not all studies specifically stated students' disability. They mentioned 'learning disability,' 'mental health' or 'medical requiring support' while others named a specific diagnosis. Overall, four key categories of disability emerged, physical impairment – e.g. mobility restriction; learning disability – e.g. dyslexia; mental health issues – e.g. depression and chronic illness – e.g. asthma. Some studies included students with combinations of physical and other disabilities.

## **Negotiating obstacles – barriers in higher education**

When researchers solicited information from students with disability about their experiences barriers in higher education was a prominent theme. Sometimes discussed as obstacles (Tinklin and Hall, 1999), found that barriers were contextual and experiences differed among groups. At the individual level, students with disability face clearly distinguishable barriers in a number of areas: the physical environment, in access to information, entrance to higher education (often discussed as barriers to transition from secondary education), assumptions of 'normality' and level of awareness. A number of the reviewed studies choose to discuss barriers from a macro perspective, identifying barriers as relational – physical, attitudinal, social, cultural and political. By presenting barriers in this manner, researchers tried to move the discussion from the particu-

lar characteristics of the student to a view of disability as a form of discrimination (Hopkins, 2011). Studies also combined attitudinal barriers with other barriers such as how a lack of resources influence support and provision, access to information, and improvement of skills and knowledge among staff and faculty. The discussion of barriers in higher education begins with a presentation of studies that investigated the impact of formal institutional arrangements for students' possibilities for engagement and representation in higher education policy-making decisions, followed by discussion of experienced barriers to transitioning into higher education and accessing the learning environment. This section also includes a brief discussion of why students with disability in higher education fail and concludes with a summary of the findings.

### ***The power of policy in higher education***

A common characteristic of the disability movements in the UK/Europe and the USA is the struggle for inclusion of people with disability without discrimination in all aspects of life. In the sphere of education in general and post-secondary/higher education in particular, legislature at the national and international levels supported these efforts. In response to a range of legislative and policy instruments devised to redress the disadvantage associated with access to education, higher education institutions adopted a number of inclusive disability policies. Within these policy frameworks definitions of disability conform to principles and rights guaranteed in international documents such as the Universal Declaration of Human Rights (UDHR, 1948), Salamanca Statement and Framework of Action (SSFA, 1994) and the Convention on the Rights of Persons with Disabilities (CRPD, 2006).

In addition to these supra-national laws, countries are required to comply with anti-discrimination laws that guarantee students with disability the right to necessary support needed to allow them to study on equal terms with students without disability. Prominent among these is the right to "reasonable accommodation" as exemplified by Section 504 and Title II of the Americans with Disabilities Act of 1990 (ADA) in the USA, the UK the Disability Discrimination Act 1995 (DDA) and the Swedish Discrimination Act 2008. Anti-discrimination laws require institutions to conform to the law but do not provide funding to finance support. Tensions and controversies arise, as commitment to supporting disabled students via reasonable accommodations are associated with monetary cost to change physical environments, hire competent faculty and staff, and invest in ICT and other forms of pedagogical tools, books etc. conflict with fiscal demands and budgetary restrictions. Consequently, while anti-discrimination legislation makes it illegal to discriminate young people because of disability and students with disability that meet admission criteria cannot be denied admission based on their disability, legislation does not guarantee funding to meet their needs in higher education.

This review shows that the numbers of students with disability in higher education is slowly increasing, as is the variety of disabilities. The variety of disabilities represented within student groups and across educational contexts reflect on the one hand, how well higher education have responded to calls for diversity given their budget constraints and on the other hand to how successful people with disability and their organizations have been in claiming rights to inclusion.

The findings show that higher education institutions are trapped between demands from students for a closer adherence to the social model of disability and its demands for inclusion, while the policy environment, limited funding and demands for fiscal accountability limits the capacity of the social model to have a pervasive impact. Borland and James argue that; "At an institutional (and a formal policy) level, universities largely holds to a social model; but the medical model is

so deeply ingrained in the everyday life experiences of both staff and students that there is a tension/conflict at the heart of the institution's provision" (Borland and James, 1999: 100, see also Beauchamp-Pryor, 2007). Thus, it is at the policy-making level that tensions between the social model and the medical model of disability are most obvious. Confronted with increasing costs of providing disability services, economic constraints force higher education institutions to resort to selection processes based on diagnoses and hierarchicalisation of disability and thus, de facto adopt a medical model approach rather than the social model they prefer.

The importance of policy for securing students' rights and the need to engage students in decision-making at this level is a central focus for several studies in this review. Studies by Brandt (2011) and Holloway (2001) are examples of how being inclusive of students views provide insight into where policy is failing or where major gaps occur. Arguments for greater engagement and representation emerged in two other arenas.

In the first, researchers argued that higher education institutions tend to see disability as a personal problem requiring an individual response. Thus, even when policy guidelines are in place, there is no guarantee of recognition of the social factors that determine the experience of disability (Holloway, 2001). According to Hutcheon and Wolbring (2012) there is a need to change existing policy embodying ideas of 'normalcy' to embody one of 'ableism', a frame they argue is more useful in understanding ability diversity (see also Madriaga et al., 2010). Second, researchers argue that policy should help students claim their rights within higher education by advocating change that break down barriers to higher education. Further, higher education institutions should actively engage and include students in policy decisions that affect them (Madriaga et al., 2010; Brandt, 2011; Hutcheon and Wolbring, 2012; Beauchamp-Pryor, 2012; Holloway, 2001; Goode, 2006). The findings show that researchers agree that there is an urgent need for student representation at the policymaking level but until now policy-makers in higher education "hear but do not listen!" (Beauchamp-Pryor, 2012).

### ***On whose terms? Transition to higher education***

Discussion of barriers to higher education was closely associated with transition. All students both those with disability and those without, experience transitioning to higher education as stressful – new environments, new ways of learning and meeting new people is a rite of passage for millions of young people every year. The transition to higher education involves not only a shift in physical and social location, for students with disability the move has implications for their personal and social identity (Borland and James, 1999). Studies in this review argued that disabled students' experiences of transition were different and more traumatic than for non-disabled students. How well they managed the transition depended on how well all partners – the student, colleges/universities, parents, service providers etc. understood their responsibilities, how responsibility was distributed between partners and the timing that emerges in relation to the student (Lang, 2013). Studies focused issues concerning responsibility for informing presumptive students of their rights to higher education, the type of support and provisioning they could demand and understanding how well higher education institutions are prepared to accept students.

The findings showed that students with and without disability are motivated to study, however their choices and options were limited by access to information (Madriaga, 2007). Students' experience of support and information in secondary education was central to their expectations of the same at the university level. Consequently, those who had received support previously

were better prepared to seek support when transitioning to higher education (Wray (2012/13). A further finding of interest was that although a lack of information affected all students, when information was limited students with disability were more disadvantaged than non-disabled students.

Another concern for disabled students when transitioning was the decision to disclose or not disclose an invisible disability. Students with learning disability or other invisible disabilities experienced specific challenges related to the choice to disclose or not. The information they received, support and guidance received, and the attitudes of others all affected the decisions made. Jacklin's (2011) study of a non-declaring postgraduate student presents an interesting case of the complexities students face. Although pros and cons differ from student to student, the study showed that for some not declaring a disability might be beneficial. For other students, fear of stigma and risk of exclusion motivates them to delay making a decision until the last possible moment, often leading to a complicated stressful student life (Vickerman and Blundell, 2010; Madriaga, 2007).

The findings show that disclosure is a delicate question with long-reaching consequences. For example, a decision not to disclose relieves teachers and other staff from the responsibility to provide reasonable accommodations as they cannot be expected to provide accommodation if they have no knowledge of the need. In such cases, students are unwittingly complicit in the problem. To alleviate the problem, researchers argue that higher education must create an environment where the decision to disclose is not an issue – where neither student nor teacher/administrator needs to feel guilty. They recommend development programs focusing pedagogy and teaching skills in combination with access to adequate information for all students as a possible solution. Without solutions, students with disability will continue to be disadvantaged and pay the price for higher education's lack of preparedness to meet their needs (Wray, 2012/13).

### ***Let me in! Gaining access to the learning environment***

The physical environment as a barrier to higher education was an important concern for early studies in the UK. The focus has changed as anti-discrimination laws and other legally binding documents require universities to adapt. As higher education has expanded, new buildings meet new legal standards and where possible, older buildings are adapted to improve access. However, research of the physical environment continues to be of interest in areas where implementation of legal standards and resources has been slower. In this review, Hadjidakou et al. (2010) provided insight into mobility issues for students in Cyprus, and Koca-Atabey et al. (2011) explored levels of stress experienced in Turkey. Other studies focused the impact of self-conceptualization for student's view of their possibilities to navigate barriers in Australia (Papasotiriou and Windle, 2012) and the effect of lack of resources for students with disability in Botswana (Moswela and Mukhopadhyay, 2011).

At the heart of these studies is the need to articulate demands for adequate support and provisioning that would guarantee disabled students access to higher education on equal footing as non-disabled students. Others discussed the quality of access and participation (Shevlin et al., 2004). In a Canadian study Mullins and Preyde (2013) discussed invisible disabilities that may be associated with learning disabilities but broadens the perspective to include barriers associated with different forms of chronic illness such as diabetes or HIV (see also Jacklin, 2011). They suggest that support organizations in higher education often fail to meet the needs of students

with different types of invisible disability. Special difficulties arise for students with combinations of physical, learning, and invisible disabilities, this group is less likely to seek or be admitted to higher education and if admitted are at greater risk to dropout and not complete their education.

### ***Flunking out – why student with disability fail in higher education***

Students with disability find that even when admitted to higher education they continue to face barriers. Riddell et al. (2002; 2005) found that even when disabled students start out with comparable qualifications to other students in the same university, they nevertheless tend to meet more barriers to learning and achieve poorer outcomes than do non-disabled students. Quinn (2013) argued that in terms of retention and completion, students with disabilities tend to face more barriers than do other students with an increased risk of dropping out. In this review, researchers claim that reasons students with disability dropout of higher education are often unrelated to their academic ability but rather to pressures associated with accessing support and accommodation and to attitudes of faculty and staff (Borland and James, 1999, Fuller et al., 2004) specifically, in relation to accessing different forms of assessment and lack of adequate support. One of the few Scandinavian studies focused disabled students' experiences of negotiating accommodations. The study provided insight into students' stress, fear of being stereotyped, pitied or excluded (Magnus and Tøssebro, 2013). The experienced stress and fear persisted even when students understood and recognized that reasonable accommodations were their right and often necessary for them to compete on par with non-disabled students (Bessant, 2012).

Attitudinal issues of faculty and staff which force students to prove their disability and thus their entitlement to services and the struggles of students to remain concentrated on their studies as they negotiate with faculty, student service offices and other service providers are well documented in the literature. Teacher and other staff attitudes towards disabled students, how well informed they are and how willing they are to meet the needs of students with disability play an important role in determining how well these students perform in higher education (Lane and Nagchoudhuri, 2015).

Teachers' attitudes and unwillingness to provide accommodation could be traced partially to teacher's skeptical attitudes towards widening participation in general (Ashworth et al., 2010). Riddell et al. (2005) suggest that some staff feared that including disabled students and adopting reasonable accommodations raised the risk of lowering academic standards (see e.g. Jensen et al., 2004; Rao, 2004). A lack of time and other resources and lack of pedagogical skills were some of the factors mentioned as needing improving to enable staff to meet new demands. Borland and James, (1999) argued that teachers, tutors and other administrative personnel are ill equipped or initiated in the social model and many have limited experience or awareness of disability and related issues. Claiborne et al. (2011) found that students highlighted a lack of resources and teachers' negative attitudes as factors that affected their inclusion (see e.g. Shevlin et al., 2004 reporting on the Irish context). The studies concluded that teacher development programs are central. In Claiborne's study, both teachers and students emphasized the need for social inclusion based on a rights perspective. In general, a positive attitude and well-informed staff/college proved crucial in ensuring access to equitable treatment (Shevlin et al., 2004). Specifically Bessant (2012) argues for more resources for professional development and techniques in curriculum designs. Teacher development programs that sensitize teachers to appreciate their legal and pedagogical obligations towards non-traditional students including students with disability should accompany all policy changes adopted in this area.

Summing up barriers to higher education, the findings reveal that the physical environment in terms of access to buildings has improved, but much remains. Issues of signage in Braille, ramps for wheelchairs, elevators, door width etc., continue to plague the physically challenged. Other physical barriers such as accessibility to websites, student portals, telephone has improved. The findings also show that many of the concerns facing disabled students are the same as those facing non-disabled students. It is also clear that for many disabled students the provision and availability of legally mandated services and accommodations is often dependent on factors unrelated to their need and entitlement. Thus, whilst officially recognizing the right to participation in higher education as a matter of equal opportunity there is no guarantee that students with disability receive the benefits and support required to exercise that right.

The studies that focused transitions to higher education revealed that all students experience some degree of social awkwardness when entering the new learning environment. However, the experiences of disabled students go beyond this to encompass perceptions of stigma and exclusion. Consequently, students with invisible disabilities were more likely to consider not disclosing disability for fear of discrimination. This recourse was not open to students with physical impairment who were unlikely to experience stigma associated with mental health or cognitive disability but were discriminated by a lack of access to the physical environment. As a conclusion studies in the review, encourage higher education institutions to work proactively towards addressing and removing potential barriers to education for all students.

Central to the experiences of disabled students was the lack of adequate information to make informed decisions. Universities usually rely on disabled student service offices to disseminate information to enrolled and presumptive students. Obviously, the ways these offices are organized, staffed and financed differ between countries and higher education institutions. What seems to be lacking at the policy-making level is the recognition that the plight of disabled students cannot remain the remit of the disabled student's office but that their needs must be integrated into everyday activities of teaching and learning. Fuller et al. (2004) identified the need for variety and flexibility in all aspects of teaching and learning and argued that what works for one student may not be a good option for another. Disabled students felt significantly disadvantaged where their learning, was restricted by inappropriate or unclear learning objectives, a lack of adapted equipment for practical activities, a lack of modification of teaching by tutors, and a lack of discussion with disabled students regarding specific barriers to learning and assessment. In relation to teaching and assessment, the findings showed that staff enthusiasm for making major changes to the curriculum and assessment was limited. Indeed, some disabled students' perceived staff as displaying considerable anxiety in relation to assessment and, in particular, about conferring an unfair advantage on disabled students in comparison with non-disabled students experiencing difficulty with the same course (Riddell, Weedon, and Fuller, 2007). Overall, the experiences reported by students revealed that teaching staff were often unaware of legislative requirements that guaranteed support for disabled students and exhibited a lack of training on how to respond to diversity in learning, teaching, and assessment.

Finally, based on the perceptions of disabled students as detailed in studies included in the review, teaching and learning is a critical and challenging issue that needs tackling in order to provide effective learning experiences (Tinklin, Riddell, and Wilson, 2004). The lack of provisions and support that adequately addressed the need of students was as a red thread throughout the discussion of barriers. Provisioning, teacher/faculty development programs were high on the list of suggestions to tackle the tension between valuing academic standards, and challenge myths that meeting the needs of disabled students in higher education is somehow lowering

academic standards. Furthermore, Konur (2002) suggest that academic achievement rather than disability assessment is a central issue to consider in ensuring institutions meets the aspirations of disabled students. Thus, whilst equality legislation is an important part of the jigsaw, it is vital that commitment to education and training of staff match these efforts in order to respond proactively to the diverse needs of the disabled students.

## Conclusions

Summing up the evidence from the literature review, the overall conclusion is that researching the experiences of disabled students and allowing them to speak for themselves provides new and important insight into what it means to be disabled and in higher education. This review has highlighted the development of research with focus on the ‘voice of’ students. Particularly, it contributes new knowledge concerning the importance of dismantling barriers in teaching and learning and an understanding of why provision of adequate information and support is a relevant issue disabled and non-disabled students alike. The empirical evidence suggest that while disabled students have the same formal rights as other students, they have fewer options, in choice of higher education institution due to barriers in the physical environment, barriers in learning due to lack of access to information, alternative assessment and educational tools. High on the list of dissatisfaction voiced by students was the attitudes of teachers and staff. In contrast, a consensus among the various studies was that the disability service office or its equivalent in the different countries did a good job, but that they were under-funded with fewer resources than those needed to meet students’ needs.

The diversity of the experiences of disabled students and the diversity of their perceptions of attitudes and challenges to learning presented by their disability draws attention to the fact that disabled students are not a homogenous group. By including students’ voices and engaging them in processes for change at all levels in higher education institutions, policies adopted can be assured to consider student needs in the specific context of that institution to the benefit of both the higher education institution and disabled students.

However, hearing the voice of students is a relatively new approach within the field of disability studies. Tight (2008) suggested that it is possible to observe the development and conceptualization of a field of research by observing and studying what he calls the “repertoire of communal resources,” that is what topics are written about, theories and methods used and journals the research is published. With that in mind, this literature review concludes that researching the voice of students remains the remit of a close-knit community. Although challenged by American variations of the social model, post-modernist and feminist critiques, the social model of disability as developed in the UK remains the model of choice for researchers. Critiques raised are not for return medical models but instead challenge disability studies to go beyond the social model to discover other ways of theorizing disability. Research continues to focus the UK context however, as disability researchers and disabled students from diverse geographical locations become involved in disability movements and demand equal rights to higher education diversity in research questions is increasing. From a European perspective, the new interest is attributed in part to the European Union’s focus on widening participation and increasing higher education options for non-traditional students. From an epistemology perspective a, participatory research methodology inclusive of a ‘voice of’ approach is appropriate for research in this review. Nevertheless, uneven power relations between participants and researchers, and fears of symbioses between researchers and participants in research where both are stakeholders may prove prob-



lematic. Based on the findings this review concludes that researchers were cognizant of their positions and were careful to declare relationships between themselves and research participants so as not to undermine or threaten the voices of disabled students.

The centrality of the *Journal Disability and Society* as a dissemination organ also plays an important role. Started by some of the leading disability researchers referenced in this literature review, authors continue to pay homage to their contributions by referencing them in their publications. Although not explicitly stated, a researcher would find it very difficult to be accepted for publication in *Disability and Society* without at least rudimentary show of faith to the social model. However, as the review shows, when higher education is the primary focus other journals such as *Studies in Higher Education*, emerges as an alternative publication. A significant finding in this review is that authors most often referenced in this review are also published and referenced in both journals. In Tight's (2008) terminology, this suggests that research on the 'voice of' disabled students is divided into two rather distinct clusters of research one focusing higher education and the other focusing disability, what holds them together is commitment to disability studies and its theoretical underpinnings.

## Limitations

As with any small-scale study, the findings and conclusions presented in this review need further verification. The small number of included studies and the dominance of researchers from the UK reveal clear limitations requiring further study. Furthermore, the closeness between participants and researchers inherent in participatory research raises legitimate questions about power relationships between the research partners and the quality of research resulting from their cooperation.

A 'voice of' approach is not enough to account for the types of practices emerging at institutions of higher education. However, this review has shown that a 'voice of' approach in participatory research has potential to engage students with disability by bringing their experiences, their everyday knowledge, and their ability into the research process and thereby gain new perspectives and insights. The included studies have attempted to account for student's voice as well as show how and when students are included and heard in their learning environments. Thus, notwithstanding its limitations, by summarizing and synthesizing the research thus far, this paper contributes new knowledge and serves as potential fodder for future research on students with disability in higher education.

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## Appendix 1. Article matrix

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
1	Baron, S., Phillips, R. & Stalker, K.	1996	Barriers to training for disabled Social Work students	Disability & Society, 11(3)	Scotland	Qualitative semi-structured interviews with students, , tutors and practice teachers to examine policy and practice regarding SWI training to become social workers	8 – SWI 8 – practice teachers 7 - tutors	Study identified 5 barriers to training; the physical environment, assumptions about impairment, failure of equal opportunity policies, practice of treating SWI as homogenous group and self-censorship on the part of SWI
2	Borland, J. & James, S.	1999	The learning experiences of students with disabilities in Higher Education. A case study of a UK university	Disability & Society, 14(1)	UK	Qualitative semi-structured interviews to examine the experiences of SWI with physical disabilities against conventional policies and policy development for independent living and in relation to the transition to HE	22 – SWI with physical impairment	The study found 4 areas of major concern; disclosure, access, quality assurance and the moral basis of HE disabilities policy.
3	Tinklin, T. & Hall, J.	1999	Getting around obstacles disabled students' experiences in Higher Education in Scotland	Studies in Higher Education, 24(2)	Scotland	Mixed-method approach using questionnaire survey, interviews and shadowing perform in-depth case studies to explore from their own perspective the experiences of SWI in HE	12 - SWI	SWI faced barriers in 5 areas: the physical environment, access to information, entrance to HE assumptions of 'normality' and level of awareness. The needs of SWI and provision of support are seen as 'additional' to the 'norm'
4	Holloway, S.	2001	The Experience of Higher Education from the perspective of disabled students	Disability & Society 16(4)	UK	Qualitative semi-structured interviews and text analysis of HE policy documentation to find out from students themselves about their experience in order to	6 - SWI	SWI experienced a model of provision that individualized disability and failed to recognize social factors that determine the experience of disability. In spite of

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
						consider the implications for practice		inclusiveness implied in policy documentation SWI experienced marginalization and disempowerment
5	Fuller, M., Bradley A. & Healey, M.	2004	Incorporating disabled students within an inclusive higher education environment	Disability & Society, 19(5)	UK	Qualitative group interviews to identify SWI's perceptions and experience of teaching, learning and assessment in HE	20 - SWI	In addition to teaching and learning SWI identified issues of access to and use of information as important to learning experience. SWI differed in willingness to seek support and had experienced widely different levels of assistance from teaching staff.
6	Shevlin, M., Kenney, M. & McNeela, E.	2004	Participation in higher education for students with disabilities: an Irish perspective	Disability & Society 19(1)	Ireland	Qualitative semi-structured interview using text analyses to register the experiences of SWI in their engagement with college, course life and work	16 - SWI	There was a low level of awareness of SWI in relation to assistive provision and assessment. SWI reports variable access experiences within HE and physical access remains a serious obstacle to participation
7	Fuller, M., Healy, M., Bradley, A., & Hall, T.	2004	Barriers to learning: a systematic study of the experiences of disabled students in one university	Studies in Higher Education, 29(3)	UK	Quantitative questionnaire survey, open-ended questions analyzed for recurring themes used to illustrate SWI's experience of barriers encountered in relation to teaching, learning and assessment in HE	173 - SWI	The study found a diversity of experiences, and the diversity of SWI perceptions of and attitudes towards their disability and its impact on learning and assessment, which has implications for formulation of HE inclusion policies
8	Mortimore, T. & Ray Crozier, W.	2006	Dyslexia and difficulties with study skills in higher education	Studies in Higher Education, 31(2)	UK	Quantitative questionnaire survey to compared perceived difficulties and need of male students with	62 – SWI 74 – non-SWI	SWI with dyslexia reported more difficulties with all learning skills and tasks prior to and during HE. Many do

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
						dyslexia with non-diagnosed students, examining experiences of learning before and during HE		not take advantage of support due to lack of awareness of availability and/or fear of stigma.
9	Goode, J.	2007	'Managing' disability: early experiences of university students with disabilities	Disability & Society 22(1)	UK	Qualitative in-depth case studies of SWIs experiences of learning and teaching to raise awareness of how SWI experience HE and to improve understanding of barriers.	20 - SWI	Findings showed that good practices lagged behind in a number of respects. SWIs spent a great deal of energy trying to 'manage' access to learning and teaching
10	Madriaga, M.	2007	Enduring disablism: students with dyslexia and their pathways into UK higher education and beyond	Disability & Society, 22(4)	UK	Qualitative life history interviews with SWIs who had transferred from secondary school to HEIs to explore students memories and experiences prior to entering HE and their perspectives on the future	21 -SWI	Presents evidence of how 'disablism' affected SWI journey to HE. Shows how 'disablism' continues to resonate in current practices and procedures within post-16 education despite legislative changes
11	Hanafin, J. Shevlin, M., Kenny, M. & McNeela, E.	2007	Including young people with disabilities: Assessment challenges in higher education	Higher Education, 54(3)	Ireland	Qualitative semi-structured interviews to ensure comprehensive overview of major issues to explore experiences of assessment practices for SWI with physical disabilities and dyslexia	16 - SWI	Showed that the implications of assessment practices for SWIs was profound, encompassing ideational, practical and social justice concerns. There is a strong case for making explicit the embedded epistemologies of assessment practices
12	Denhart, H.	2008	Deconstructing barriers perceptions of students labeled with learning disabilities in higher education	Journal of Learning Disabilities, 41(6)	USA	Qualitative interviews The using a phenomenological approach to identify commonly held structures of consciousness among college students with learning disabilities, educational	11 - SWI	A striking finding was the overwhelming reluctance of SWIs to request or use accommodations. Fear of stigma labelling as learning disabled.

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
						barriers and the ways they overcome them.		
13	Hadjikakou, K. & Hartas, D.	2008	Higher education provision for students with disabilities in Cyprus	Higher Education, 55(1)	Cyprus	Qualitative students selected from larger survey study, used interviews and focus groups to study the prevalence and experiences of SWI and special educational needs in HE and the support services provided	15 SWI	Results pointed to variability in access to resources and availability of services, also a lack of clarity in identifying areas of need, limited consistency in procedures and type of support available. Ad hoc response at both the individual and organizational level
14	Hadjikakou, K., Polycarpou, V. & Hadjilia, A.	2010	The experiences of students with mobility disabilities in Cypriot higher education institutions: Listening to their voices	International Journal of Disability, Development and Education, 57(4)	Cyprus	Qualitative in-depth semi-structured interviews to explore the experiences of SWI with mobility disabilities in HE	10 - SWI	SWI did not have the same range of options as non-SWI. Choice of HE on basis of reasons related to disability. Changing institutional practice requires fundamental changes in the understanding of disability at all levels of HEIs.
15	Collinson, C. & Penketh, C.	2010	'Sit in the corner and don't eat the crayons': Postgraduates with dyslexia and the dominant 'lexic' discourse	Disability & Society, 25(1)	UK	Qualitative narrative/learner histories from earliest memories to present	6 – post graduates and academics with learning disability	The narratives reflected how particular experiences contributed to learning experiences. Found a dominant role for attitudes and concepts relating to literacy and academic ability for individual outcomes.
16	Vickerman, P & Blundell, M.	2010	Hearing the voices of disabled students in higher education	Disability & Society, 25(1)	UK	Quantitative survey and interviews	504 - students (SWI and non-SWI) 4 - face-to-face interviews	Uninformed students experienced stress, anxiety and difficulty to prepare for HE. Good experiences depended on attitudes and experiences of staff rather

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
								than policies and provisions
17	Madriaga, M. Hanson, K. Heaton, C., Kay, H., Newitt, S., & Walker, A.	2010	Confronting similar challenges? Disabled and non-disabled students' learning and assessment experiences	Studies in Higher Education, 35(6)	UK	Quantitative survey, open-ended responses thematically analyzed	172 – SWI 312 – Non-SWI	SWI experience greater difficulty than non-SWI in amount of time needed for coursework, note taking, reading course material accessing buildings etc. All students benefited from supportive and inclusive practices.
18	Ashworth, M., Bloxham, S. & Pearce, L.	2010	Examining the tension between academic standards and inclusion for disabled students: The impact of marking of individual academic frameworks for assessment	Studies in Higher Education, 35(2)	UK	Qualitative mixed methods – observations, interviews with students, academic and support staff, discussion groups and a questionnaire to report on a creative art module for SWI with complex disabilities	6 – SWI	Inclusion of SWI in HE rests on 'reasonable adjustments' to teaching and assessment. which improves educational opportunity but does not lower educational standards. re
19	Gibson, S. & Kendall, L.	2010	Stories from school: dyslexia and learners' voices on factors impacting on achievement	Support for Learning, 25(4)	UK	Qualitative Historical narratives	5 – SWD/LD	Transition from secondary to higher education
20	Claiborne, LB, Cornforth, S., Gibson, A. & Smith, A.	2011	Supporting students with impairments in higher education: social inclusion or cold comfort	International Journal of Inclusive Education, 15(5)	New Zealand	Qualitative interview study Discourse analysis to examine experience of 'inclusion' from several stakeholders at one university	4 – SWI 3 – non SWI 7 – Teachers 3 – Staff	For all groups questions of disclosure of disability were of greater concern than were tensions between needs and rights of students.
21	Hopkins, L.	2011	The path of least resistance: A voice-relational analysis of disabled students' experiences of discrimination in English universities	International Journal of Inclusive Education, 15(7)	UK	Qualitative narrative (stories) interpretive interview approach using a voice-relational method to analysis the generated data	6 – SWI from 4 universities	Explored SWI life before university, coming to university and experiencing barriers. Concluded that SWI need to develop overt assertiveness to ensure that their needs are met. HE need

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
								to provide more supportive culture for SWI.
22	Brandt, S.	2011	From policy to practice in higher education: The experiences of disabled students in Norway	International Journal of Disability, Development and Education, 58(2)	Norway	Qualitative in-depth interviews and text analysis of policy documents to explore student's experience of organizational and educational accessibility	19 - SWI 6 – 6 staff	Educational reform strengthened potentials for learning but poor communication between and within university departments contributed to poor communication and stress
23	Moswela, E. Mukhopadhyay, S.	2011	Asking for too much? The voices of students with disabilities in Botswana	Disability & Society, 26(3)	Botswana	Qualitative semi-structured focus group interview schedule to explore whether SWI's had equal access to participate in HE	7 - SWI	Lack of physical access, non-compliance with university policies, lack of support for SWI in curriculum development but positive support from SWI Office. SWI voices not heard in policy formulation
24	Jacklin, A	2011	To be or not to be 'a disabled student' in higher education: the case of a postgraduate 'non-declaring' (disabled) student	Journal of Research in Special Educational Needs, 11(2)	UK	Qualitative case study to explore and analyse the experience of one non-declaring SWI	1 – one post-graduate SWI	The case illustrated how the degree an impairment can be hidden or masked and social effects interact with expectations of HE's within a complex arena of decision-making about whether to declare or not
25	Madriaga, M., Hanson, K., Kay, H., & Walker, A.	2011	Marking-out normalcy and disability in higher education	British Journal of Sociology of Education, 32(6)	UK	Mixed-method quantitative comparing survey feedback with student academic records and individual interviews to explore the dichotomy between what students say and what they have achieved	172 – SWI 313 – non SWI	SWI's with learning difficulties and disability specific support experience more difficulty with literacy compared with other students. Found no significant difference in achievement when comparing non-SWI and SWI.

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
								But significant difference in achievement between non-SWI and SWI who do not receive disability support
26	Koca-Atabey, M., Nuray Karanci, A., Dirik, G., & Aydemir, D.	2011	Psychological wellbeing of Turkish university students with physical impairments: An evaluation within the stress-vulnerability paradigm	International Journal of Psychology, 46(2)	Turkey	Quantitative survey snowball sampled to examine variables related to psychological well-being in terms of psychological distress and stress-related growth among SWI with physical impairments	70 - SWI	Disability burden, hassles and helplessness coping were significant predictors of psychological symptoms. Problem solving coping was significant related to stress related growth
27	Habib, L., Berget, G., Sandnes, FE., Sanderson, N., Kahn, P., Fagernes, S., & Olcay, A.	2012	Dyslexic students in higher education and virtual learning environments: an exploratory study	Journal of Computer Assisted Learning 28(6)	Norway	Qualitative exploratory interview study to explore the use of virtual learning environment (VLE) among dyslexic students	12 - SWI	A need of improvement in physical design of VLE and in pedagogical and didactical design of courses and practical support to SWI
28	Cook, V., Griffin, A., Hayden, S., Hinson, J., & Raven, P.	2012	Supporting students with disability and health issues: lowering the social barriers	Medical Education 46(6)	UK	Mixed-methods thematic analysis of semi-structured interviews and a questionnaire survey to explore the effectiveness of a newly introduced Student Support Card	31 - SWI	Findings showed that the scheme was flexible and addressed unique student needs. Further research needed to ascertain how educators perceived benefits of the card
29	Hutcheon, EJ. & Wolbring, G.	2012	Voices of “disabled” post-secondary students: Examining higher education “disability” policy using an Ableism lens	Journal of Diversity in Higher Education, 5(1)	Canada	Qualitative semi-structured in-depth interviews to explore the ways ‘disabled’ students make meaning of their experiences in post-secondary education	8 - SWI	The analysis generated 5 themes situated within a body-self-social framework demonstrating a continued need for critical examination of HE policy and its capacity to address differences in ability
30	Papasotiriou, M. & Windle, J.	2012	The social experience of physically disabled Australian university students	Disability & Society, 27(7)	Australia	Qualitative semi-structured interviews to investigate social capital, self-concept	4 - SWI	Findings revealed that students had weak social attachments at university but

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
						and the potential relationship between the two		stronger attachments among family and friends outside university. Self-concept was not structured by university generated social capital
31	Gibson, S.	2012	Narrative accounts of university education: socio-cultural perspectives of students with disabilities to address transitions and questions of access to HE for students with identified disability	Disability & Society, 27(3)	UK	Qualitative semi-structured interviews and mind map visual tool Using the concept 'disablism' to explore access to university, learning experiences with teachers, peers and educational/ institutional practices.	5 – SWI under graduates	Main conclusion, socio-cultural processes are significant factors promoting experiences of exclusion an inclusion
32	Beauchamp-Pryor, K.	2012	From absent to active voices: securing disability equality within higher education	International Journal of Inclusive Education, 16(3)	UK	Mixed-methods interviews of students identified in larger survey and interviews of key informants to investigate the representation and participation of disabled students in development of HE policy	23 – SWI 4 - key informants	Findings of the study highlighted barriers based on power sharing and traditional ideology. Claims that these relations will be challenged as SWI voices become more active in HE
33	Bessant, J.	2012	'Measuring Up'? Assessment and students with disabilities in the modern university	International Journal of Inclusive Education, 16(3)	Australia	Qualitative auto-ethnographic case study method to study how HE is 'measuring up' with regard to SWI's and assessment of their learning	3 - SWI	Resources for professional development and curriculum design and support for teaching staff. At present the indication is that students are in greater need of support as they negotiate university processes.
34	May, C.	2012	An investigation of attitude change in inclusive college classes including young adults with intellectual disability	Journal of Policy and Practice in Intellectual Disability 9(4)	USA	Quantitative 45-item survey used to measure universal-diverse orientation (UDO) to explore whether inclusion of students with intellectual disability impacted attitudes	138 – non-SWI 8 – SWI with intellectual disability	Inclusive college programs that enroll both non-SWI and SWI with intellectual disability in regular course may foster positive attitudes about acceptance and



ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
						of non-SWI about diversity in regular classes		diversity among non-SWI students
35	Carter, C. & Sellman, E	2013	A view of dyslexia in context: Implications for understanding differences in essay writing experience amongst higher education students identified as dyslexic	Dyslexia, 19(3)	UK	Qualitative semi-structured interviews draws on grounded theory to explore how differences in essay writing experience is constituted for a group of students identified as dyslexic	22 – students 14 w/dyslexia 8 non-dyslexic	Problem with isolating within person dyslexia related difficulties from social practices of writing and dyslexia. Setting social practices alongside a view of dyslexia as socially constructed is a more productive way of addressing the writing needs of the group
36	Mullins, L. & Preyde, M.	2013	The lived experience of students with an invisible disability at a Canadian university	Disability & Society 28(2)	Canada	Qualitative in-depth semi-structured interviews to explore dyslexia, attention-deficit hyperactivity disorder and mental illness to reveal the perceptions of the experiences of students in the university context.	10 - SWI	A notable paradox – to reduce questions about validity participants reported a desire to have a visible manifestation of their disability, but participants wanted to be able to choose when to disclose their disability
37	Magnus, E. & Tössebro, J.	2013	Negotiating individual accommodation in Higher Education	Scandinavian Journal of Disability Research	Norway	Qualitative using time-geographic diaries, in-depth interviews and focus groups to explore how SWI negotiate accessibility in HE and how everyday life is shaped by individual preferences and barriers encountered	19 - SWI	Exposed tensions between unaltered traditions in HE and new recent policy. Demonstrated the ambiguity and ambivalence in SWI's reflections on identity, belonging, to disclose or not disclose disability when the option is available
38	Lang, L.	2013	Responsibility and participation in transition to university – voices of young people with disabilities	Scandinavian Journal of Disability Research	Sweden	Qualitative narrative approach to draw attention to experiences regarding responsibility and	4 - SWI	Although formally qualified, whether students gain access to university is influenced by factors in their surrounding

ID	Author (s)	Year	Title	Periodical	Land	Method	Participants	Findings
						participation in the transition from secondary school to university		environment. University environment experienced as unprepared to fit the needs of SWI
39	Simmeborn Fleischer, A., Adolfsson, M. &Granlund, M.	2013	Students with disabilities in higher education – perceptions of support needs and received support: A pilot study	International Journal of Rehabilitation Research, 36(4)	Sweden	Mixed –method approach to develop a questionnaire survey instrument designed to investigate how SWI perceive their everyday life at HE	34 - SWI	To succeed in HE SWI with Asperger Syndrome, hearing impairment and motor disability need support in their daily and student lives. The lack of clear links between the type of disability and perceived restrictions indicate the need for individualized support
40	Wray, M.	1012 /13	Comparing disabled students' entry to higher education with their non-disabled peers – barriers and enablers to success	Widening Participation and Lifelong Learning, 14(3)	UK	Qualitative focus groups interviews to compare experiences of SWI learners with their non-SWI peers in HE with SWI and non- SWI who had decided not to enter HE	16 - non- SWI HE 12 – SWI HE 6 – SWI non HE 6 - non SWI HE	SWI reported significantly more difficulties in their progression to HE than non-SWI. Both groups met enabling factors that assisted their educational progress. Findings were reinforced within the non-HE groups. Significant others specifically teachers played an important role in raising or dampening aspirations
41	Redpath, J., Kearney, P., Nicholl, P., Mulvenna, M., Wallace, J. & Martin, S.	2013	A qualitative study of the lived experiences of disabled post-transition students in higher education institutions in Northern Ireland	Studies in Higher Education, 38(9)	N. Ireland	Qualitative in-depth case studies to provide a clear depiction of support provision for SWI's in universities	13 - SWI	Major factor impacting employing inclusive assessment practices is resistance to changes by staff, as these practices may result in more planning and additional time for marking and evaluation